



NTACT

National Technical Assistance Center on Transition

Health Issues in Transition Annotated Bibliography

Prepared for NSTTAC, 2009, by James White, UNC Charlotte and Debbie Gilmer, Healthy and Ready to Work National Resource Center
Updated for NTACT, 2015, by Bradley Stevenson

What is “Health Issues in Transition”?

Health issues in transition focuses on issues related to individuals with special health care needs as they transition from pediatric to adult services. The Maternal and Child Health Bureau defines youth with special health care needs as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson et al., 1998, p. 138). When individuals with these types of conditions reach the age of majority they must transition to the adult health care system. As such, the goal of healthcare transition is provide high-quality, developmentally appropriate, and uninterrupted services as the individual transitions to adulthood in order to maximize the individual’s potential and lifelong functioning (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine, 2002).

Why is “Health Issues in Transition” in Transition Planning Important?

Managing one’s health can be a challenge for many young people with disabilities, especially those with special health care needs. It involves many skills such as effective communication with medical professionals, managing medications, maintaining treatment plans, navigating finances and bureaucracy to name a few. Adding to this complexity is the fact that there are different expectations in the pediatric and adult health care systems (Betz, 1998). Therefore, it is not surprising that youth with disabilities have poor health care outcomes when transitioning to adult life (Bryan, Stiles, Burstein, Ergul, & Chao, 2007). As such, active planning for managing health issues during the transition to adulthood is critical.

References

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. (2002). A consensus

statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110, 1304-1306.

Betz, C. L. (1998). Facilitating the transition of adolescents with chronic conditions from pediatric to adult health care and community settings. *Issues in Comprehensive Pediatric Nursing*, 21, 97-115.

Bryan, T., Stiles, N., Burstein, K., Ergul, C., & Chao, P. C. (2007). "Am I supposed to understand this stuff?" Youth with special health care needs readiness for transition. *Education and Training in Developmental Disabilities*, 42, 330-338.

McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J., & Strickland B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102, 137-140.

What Does the Literature Say About Health Issues in Transition in Transition Planning?

Over the past two decades, quite a bit has been published on the topic of health issues in transition. The following sections will provide a reference and a brief synopsis of articles published on this topic. The articles are divided into three categories: discussion, research, and transition planning materials. Discussion articles consist of articles that describe a relevant issue or position. Research articles consist of studies that were published on the topic including (e.g., experimental, qualitative, correlational, reviews). Last, transition planning materials include articles that describe or present specific resources to facilitate transition for students with special health care needs.

Discussion Articles

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110, 1304-1306.

- Provides a consensus statement approved as policy by the boards of the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine on the critical first steps that the medical profession needs to take to realize the vision of a family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care system that is as developmentally appropriate as it is technically sophisticated for young adults with special health care needs to maximize lifelong functioning and potential

through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.

Betz, C. L. (1998). Facilitating the transition of adolescents with chronic conditions from pediatric to adult health care and community settings. *Issues in Comprehensive Pediatric Nursing, 21*, 97-115.

- Provides an overview of the health care issues and concerns of adolescents with special health care needs and disabilities who are in transition from pediatric to adult health care settings
- The author provides a sample assessment for self-care management skills and describes intervention strategies pediatric nurses can use to facilitate the transition to adult health care. These include providing referrals to relevant resources, anticipatory guidance on dangerous behaviors (e.g., addictive substances), healthcare counseling on relevant topics (e.g., sexuality), assisting with locating and using accommodations, discussing concerns with the parents

Betz, C. L. (1999). Adolescents with chronic conditions: Linkages to adult service systems. *Pediatric Nursing, 25*, 473-476.

- Provides an overview of services available to assist high school students with chronic conditions in making the transition to postsecondary settings.

Betz, C. L. (2000). California healthy and ready to work: Transition health care guide: Developmental guidelines for teaching health care. *Issues in Comprehensive Pediatric Nursing, 23*, 203-244.

- Provides developmental guidelines that can be used by parents and nurses to teach health care self-care skills to children and youth
- These guidelines are intended to provide a framework for instructing parents and nurses about the developmentally appropriate skills children can learn to become self-sufficient in managing their own health care needs

Betz, C. L. (2001). Use of 504 plans for children and youth with disabilities: Nursing application. *Pediatric Nursing, 27*, 347-352.

- Provides information about the history of 504 plans
- Provides requirements for primary, secondary, and postsecondary settings
- Describes the role of nurses in schools and clinical settings in developing 504 plans

Betz, C. L. (2003). Nurse's role in promoting health transitions for adolescents and young adults with developmental disabilities. *Nursing Clinics of North America*, 38, 271-89.

- Discusses the nurse's role in promoting healthy and culturally competent transitions for adolescents with developmental disabilities
- Examines the impact of cultural factors influencing the youth's transition process
- Includes recommendations for addressing these needs within the context of nursing practice beginning with a comprehensive, culturally competent assessment of adolescent and family needs in order to foster youth autonomy and family support during this important stage of development

Betz, C. L. (2004). Adolescents in transition of adult care: Why the concern? *Nursing Clinics of North America*, 39, 681-713.

- Described issues associated with transition planning for youth with congenital heart disease (CHD).
- Describes a number of approaches to address the needs of this growing number of youth with CHD including; issues related to employment, education, social relationships, and independent living
- Provides recommendations for successful transitioning including youth-centered approaches, service coordination, and referral to adult agencies

Betz, C. L. (2007). Facilitating the transition of adolescents with developmental disabilities: Nursing practice issues and care. *Journal of Pediatric Nursing*, 22, 103-115.

- Provides an overview of salient issues that adolescents with developmental disabilities face as they approach adulthood and the roles health care professionals have as service coordinators, consultants, or direct service providers to ensure that the health-related transition needs of the youth are met.
- Provides transition assessment, planning, and intervention strategies that nurses can integrate into a comprehensive plan of care are discussed. These include: (a) incorporating self-determination interventions; (b) assessing the adolescents adult goals, preferences, interests, and needs via transition assessment; (c) involve families in the process; (d) involving the student in the process; (e) incorporate career awareness activities; and (f) collaborating with adult service providers (e.g., vocational rehabilitation).
- The author notes that nurses should be particularly focused on ensuring adolescents with developmental disabilities are being able to manage one's own health care needs, youths continuing to receive comprehensive and affordable healthcare, and being able to complete health insurance tasks.

Betz, C. L., & Redcay, G. (2005). Dimensions of the transition service coordinator role. *Journal of Specialty Pediatric Nursing, 10*, 49-59.

- Describes a role for advanced practice nurses as transition service coordinators (TSC) to provide highly specialized transition services to this group of youth in pediatric settings

Blomquist, K. B. (2006). Healthy and Ready to Work – Kentucky: Incorporating transition into a state program for children with special health care needs. *Pediatric Nursing, 32*, 515-528.

- Describes a federally funded state program designed to improve coordination of services and transition programming for youth with special needs in which nurses, in their direct care and care coordination roles with youth and families, focus on:
 - Health promotion
 - Health care and condition management
 - Transition to adult care with funding
 - Development of life skills
 - Opportunities for participation in the community
- Describes how nurses in community outreach focus on:
 - Collaborative planning
 - Access to information
 - Setting higher standards and expectations for services
 - Documentation
 - Evaluation

Blum, R., White, P. H., & Gallay, L. (2005). Moving into adulthood for youth with disabilities and serious health concerns. *Network on Transitions to Adulthood Policy Brief, 26*. Philadelphia, PA: University of Pennsylvania, MacArthur Research Network on Transitions to Adulthood and Public Policy. Retrieved May 19, 2009 from <http://www.transad.pop.upenn.edu/downloads/blum%20disabilities%20final.pdf>.

- Summarizes critical steps for successful transition planning for youth with disabilities or serious medical conditions which include:
 - Planning should start early
 - Involve the youth
 - Include vocational programs
 - Build a strong support system for the youth that includes the medical community, family, friends, peers, and the larger community in which they live

Ferris, M. E., Ferris, M. T., Okumura, M. J., Cohen, S. E., & Hooper, S. R. (2015). Health care transition preparation in youth with chronic conditions: Working towards translational evidence with a patient perspective. *Journal of Pediatric Rehabilitation Medicine*, 8, 31-37. doi:10.3233/PRM-150316

- This article is a commentary on the state of health care transition. It incorporates multiple views on the topic including an individual with a chronic condition who has transitioned to adult services, that individual's parent, and interdisciplinary health providers.
- Additionally, the authors reviewed the literature to: (a) identify key factors; (b) analyze current trends and initiatives; and (c) make suggestions for future research, practice, and policy.

Gall, C., Kingsnorth, S., & Healy, H. (2006). Growing up ready: A shared management approach. *Physical and Occupational Therapy in Pediatrics*, 26, 47-62.

- Presents a transition framework designed to facilitate a shared management approach to assist youth with physical disabilities and their families plan for transition to adulthood.

Gorter, J. W. (2009). Transition to adult-oriented health care: Perspectives of youth and adults with complex physical disabilities. *Physical & Occupational Therapy in Pediatrics*, 29, 362-366. doi:10.3109/01942630903222100

- In this position paper the author discusses the transition from pediatric to adult health care services for youth and adults with complex physical disabilities.
- He contends that young people are often able to assume responsibility for their own health and lives in general. As such, he argues health care providers should listen to young people's views.

Gorter, J. W., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: Care, health and development. *Child: Care, Health and Development*, 37, 757-763. doi:10.1111/j.1365-2214.2011.01336.x

- This is an introductory article to the special issue on transition to adulthood for youth with disabilities and chronic conditions. The authors present an overview of the topic. They discuss the health of this population, understanding of human development and its effects on these individuals, and the health care at the person, program, and policy level.

Hamdani, Y., Jetha, A., & Norman, C. (2011). Systems thinking perspectives applied to healthcare transition for youth with disabilities: A paradigm shift for practice,

policy and research. *Child: Care, Health and Development*, 37, 806-814.
doi:10.1111/j.1365-2214.2011.01313.x

- This paper provides an introduction to the concepts of systems-thinking as it relates to health care transition and research.
- Systems-thinking is a theoretical perspective that accounts for the complexity and interactions between health care transition factors.
- The authors contend that an understanding of the complex interplay of various health care transition factors can lead to identifying areas for intervention and analyzing the impact of these interventions.

Kennedy, M. T. (2012). Health care transitioning: Preparing youth with disabilities for a healthy tomorrow. *Exceptional Parent*, 42(6), 26.

- The article has discusses the challenges inherent in the transition from pediatric to adult health care services for individuals with chronic health conditions.
- The author describes the barriers for youth with disabilities and chronic conditions as they transition to adult health care systems.
- She suggests parents begin preparing their child as early as 14 years old by creating a health care transition plan that addresses: (a) the child's ability to learn about his/her health and/or disability, (b) the child's ability to learn what types of care and treatments are necessary, (c) the different types of health insurances, (d) increasing the child's responsibility for his/her health needs, (e) communicating with health care professionals, and (f) managing his/her own medication(s).

King, G. A., Baldwin, P. J., Currie, M., & Evans, J. (2005) Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care*, 34, 193-216.

- Provides a conceptual model and review of the effectiveness of approaches for providing transition education and planning services for youth with disabilities. The model incorporates four approaches:
 - Skills training
 - Prevocational/vocational guidance
 - Client-centered approach
 - Ecological/experiential approach
- The model links these approaches to commonly used transition strategies, which reflect the personal, person–environment, and environmental levels of intervention

Lotstein, D. S., Inkelas, M., Hays, R. D., Halfon, N., & Brook, R. (2008). Access to care for youth with special health care needs in the transition to adulthood. *Journal of Adolescent Health, 43*, 23-29.

- Describes access to care and identifies factors associated with access for low-income young adults who aged out of a public program for children with special health care needs. Survey results found:
- Insurance gaps and delayed care are prevalent among these low-income young adults despite ongoing health problems
- Greater transition support might improve access by linking them with a usual source of care, identifying insurance options, and encouraging regular use of care

O'Connell, B., Bailey, S., & Pearce, J. (2003). Straddling the pathway from pediatrician to mainstream health care: Transition issues experienced in disability care. *Australian Journal of Rural Health, 11*, 57-63.

- Describes strengths and limitations of health care and related services provided to young adults with disabilities during the period of transition from the care of a pediatrician to the mainstream health system
- Findings revealed a number of problems with the transition period:
- Lack of knowledge and support among pediatricians to manage the adolescent with a disability
- Communication problems between all service providers
- The general lack of continuity of care between providers

Ptomey, L. T., & Wittenbrook, W. (2015). Position of the Academy of Nutrition and Dietetics: Nutrition services for individuals with intellectual and developmental disabilities and special health care needs. *Journal of the Academy of Nutrition & Dietetics, 115*, 593-608. doi:10.1016/j.jand.2015.02.002

- This position paper describes the role of registered dietitian nutritionists and nutrition and dietetics technicians in the care for individuals with disabilities and special health care needs, both youth and adult.
- It describes the justifications for services including the unique risks faced by this population and the benefits professionals can offer. It also makes recommendations for how services should be delivered.

Soanes, C., & Timmons, S. J. (2004). Improving transition: A qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *Child Health Care, 9*, 102-112.

- Describes the attitudes of young people with chronic illness facing transition and ways in which provision could be improved from a service-user's perspective
- Findings indicate to increase the likelihood of successful transition, strategies need to be informal, flexible, highly individualized and prepare adolescents steadily for adult services

U.S. Department of Health and Human Services. (2005). The Surgeon General's Call To Action to Improve the Health and Wellness of Persons with Disabilities.

- Presents four goals to help people with disabilities experience full, rewarding, and healthy lives as contributing members of their communities:
 - Increase understanding nationwide that people with disabilities can lead long, healthy, and productive lives
 - Increase knowledge among health care professionals and provide them with tools to screen, diagnose, and treat with dignity the whole person with a disability
 - Increase awareness among people with disabilities of the steps they can take to develop and maintain a healthy lifestyle.
 - increase accessible health care and support services to promote independence for people with disabilities

Ziring, P. R., Brazdziunas, D., & Cooley, W. C. (2000). The role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. *Pediatrics*, 106, 854-856.

- Describes the role of pediatricians in the successful transition from school to adult settings for young people with developmental disabilities and chronic illnesses includes promotion of self-advocacy and self-determination as well as knowledge of key federal laws effecting vocational education

Research Articles

Betz, C. L., Redcay, G., & Tan, S. (2003). Self-reported health care self-care needs of transition-aged youth: A pilot study. *Issues in Comprehensive Pediatric Nursing*, 26, 159-181.

- Describes the self-reported health care self-care needs and skills of transition-aged youth referred for transition services
- Findings revealed that youth with developmental disabilities had significantly higher numbers of "no" responses in seven domains than youth with cancer and youth with cancer had significantly higher numbers of "yes" responses in six domains than youth with developmental disabilities

Betz, C. L. (2004). Transition of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing, 27*, 179-241.

- Provides a review and analysis of 43 transition studies published from 1982 through 2003
- Describes limitations associated with these studies, including the lack of theoretical frameworks, the use of valid and reliable instruments, and research designs lacking adequate controls

Bloom, S. R., Kuhlthau, K., Van Cleave, J., Knapp, A. A., Newacheck, P., & Perrin, J. M. (2012). Health care transition for youth with special health care needs. *Journal of Adolescent Health, 51*, 213-219.

- The authors reviewed the literature to (a) determine adult outcomes for youth with special health care needs without special transition interventions, and (b) identify evidence for strategies that lead to better outcomes, specifically access to adult health care.
- Fifteen articles were included. The authors found that some youth with special healthcare needs have gaps in outcomes, particularly it appears youth with complex conditions or with conditions that affect the nervous system have less successful transitions.
- The authors concluded the evidence concerning programs to facilitate transition for youth with special health care needs remains inconclusive, but some weak evidence does imply that meeting adult providers before transfer may facilitate posttransition access to care.

Bryan, T., Stiles, N., Burstein, K., Ergul, C. & Chao, P. C. (2007). "Am I supposed to understand this stuff?" Youth with special health care needs readiness for transition. *Education and Training in Developmental Disabilities, 42*, 330-338.

- Presents the results for a phone survey in which youth with special healthcare needs were asked about their:
 - Educational and vocational goals
 - Current healthcare
 - Life experiences
 - Social life

Callahan, S. T. & Cooper, W. O. (2007). Continuity of health insurance coverage among young adults with disabilities. *Pediatrics, 119*, 1175-1180.

- Presents the results of a 36-month longitudinal study that compared the continuity of health insurance coverage of students with and without disabilities

Cheak-Zamora, N. C., Fanner, J. E., Mayfield, W. A., Clark, M. J., Marvin, A. R., Law, J. K., & Law, P. A. (2014). Health care transition services for youth with autism spectrum disorders. *Rehabilitation Psychology, 59*, 340-348. doi:10.1037/a0036725

- This study interviewed 101 parents of youth with autism spectrum disorders (ASD) to examine the frequency youth with ASD receive health care transition (HCT) services and the variation in services by individual, family, and health care system characteristics.
- Results indicated that: (a) fewer than 15% of youth received HCT services; (b) 41% had minimally one HCT discussion; (c) only 3% had 3; (d) 25% had a discussion with their health care provider about transitioning to an adult provider, adult health care needs, or insurance retention; and (e) 31% of providers encouraged youth to take on more responsibilities..
- Authors conclude that caregivers do not realize the importance of HCT services. Therefore education and training is needed for caregivers, youth, and providers to ensure they work collaboratively to address necessary transition issue.

Cheak-Zamora, N. C., Yang, X., Farmer, J. E., & Clark, M. (2013). Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics, 131*, 447-454. doi:10.1542/peds.2012-1572

- This study compared the health care transition services received by youth with autism spectrum disorders and youth with other special health care needs (OSHCN).
- Logistic regression analyses were conducted on the association of individual, family, and health system factors with the receipt of health care transition services.
- Results revealed differences between the two populations with youth with OSHCN receiving more health care transition services and discussions about health care transition than youth with autism spectrum disorders.
- The authors recommend additional research to understand facilitators and barriers to quality health care transition services, to develop policy, and to facilitate guidelines for care.

Davis, M. & Sondheimer, D. L. (2005). State child mental health efforts to support youth in transition to adulthood. *Journal of Behavioral Health Services Research, 32*, 27-42.

- Presents the findings from interviews to determine the ability of state child mental health (MH) systems to facilitate the transition to adulthood of

adolescents in their systems and identifies three roadblocks to successful transition:

- Continuity of services as youth age into adulthood is hampered because of generally separate child and adult MH systems
- Lack of clarity about procedures to access adult MH services
- Lack of shared client planning between adult and child MH systems

Hamdani, Y., Proulx, M., Kingsnorth, S., Lindsay, S., Maxwell, J., Colantonio, A., & ... Bayley, M. (2014). The LIFEspan model of transitional rehabilitative care for youth with disabilities: Healthcare professionals' perspectives on service delivery. *Journal of Pediatric Rehabilitation Medicine*, 7, 79-91. doi:10.3233/PRM-140271

- This qualitative study looked at the experiences of healthcare professionals engaged in LIFEspan service delivery, a “real world” service delivery method meant to facilitate transitional rehabilitative care for youth with disabilities.
- The authors concluded that LIFEspan contributed to activities that coordinated care and integrated services, but gaps in services persisted especially with primary care, education, social, and community services in relation to the rehabilitation sector.
- Recommendations are made regarding how to improve services via a systems/sector-based approach.

Lotstein, D. S., Kuo, A. A., Strickland, B., & Tait, F. (2010). The Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist?. *Pediatrics*, 126, S129-S136. doi:10.1542/peds.2010-146SF

- One contributing factor to poor health care transition outcomes for youth with special health care needs (YSHCN) is interrupted access to high-quality health care, an issue faced by minorities.
- The authors reviewed research to examine racial and ethnic disparities in the transition preparation and outcomes for youth with special health care needs (YSHCN).
- Results indicate (a) few YSHCN receive adequate transition preparation, (b) there are some data indicating this is worse for minorities, (c) young adults have poorer access to healthcare than children, (d) the decline in healthcare as youth grow is exacerbated for Hispanic and African American young adults, and (e) low-income YSHCN are at higher risk than other YSHCN of experiencing interrupted access to care.

Mcmanus, M. A., Pollack, L. R., Cooley, W. C., Mcallister, J. W., Lotstein, D., Strickland, B., & Mann, M. Y. (2013). Current status of transition preparation among youth with

special needs in the United States. *Pediatrics*, 131, 1090-1097.
doi:10.1542/peds.2012-3050

- Examined the performance of the United States regarding successful transition from pediatric to adult care using data from the National Survey of Children with Special Health Care Needs from 2009-2010.
- Results indicated the majority of youth with special health care needs did not receive the preparation necessary for a successful transition (e.g., discussions about insurance).
- The authors point to recommendations by the Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians (2011) to foster improvement in this area.

Morningstar, M. E., Turnbull, H. R., Lattin, D. L., Umbarger, G. T., Reichard, A., & Moberly, R. L. (2001). Students supported by medical technology: Making the transition from school to adult life. *Journal of Developmental and Physical Disabilities*, 13, 229-259.

- Reports on results from a longitudinal interview study regarding the transition experiences of family members and students supported by medical technology. Three major themes emerged:
 - Future expectations of students and parents
 - Implementation of transition planning
 - Participation and involvement in transition planning
- Results indicate that the majority of students supported by medical technology appeared to be receiving minimal planning during transition

Nishikawa, B. R., Daaleman, T. P., & Nageswaran, S. (2011). Association of provider scope of practice with successful transition for youth with special health care needs. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, 48, 209-211. doi:10.1016/j.jadohealth.2010.06.011

- Examines the relation between the scope of a caregiver's medical practice (i.e., child-only or lifespan-oriented) and healthcare related transition related services.
- Results indicated that discussions related to transition to adult healthcare are more likely to occur with youth with special health care needs if the provider treats adults and children. However, there was a lack of discussion regarding adult health insurance for all youth with special health care needs.

Oswald, D. P., Gilles, D. L., Cannady, M. S., Wenzel, D. B., Willis, J. H., & Bodurtha, J. N. (2013). Youth with special health care needs: Transition to adult health care services. *Maternal and Child Health Journal*, 17, 1744-1752. doi:10.1007/s10995-012-1192-7

- This study was conducted to define successful health care transition and to identify factors that contribute to successful transition.
- The researchers used data from the 2007 Survey of Adult Transition and Health dataset to identify predictors of success.
- Results showed only small portion of young adults successfully transitioned to adult care.

Powers, K., Geenen, S., & Powers, L. E. (2009). Similarities and differences in the transition expectations of youth and parents. *Career Development for Exceptional Individuals, 32*, 132-144. doi:10.1177/0885728809346302

- This study compared the transition expectations of parents and youth with disabilities.
- The researchers surveyed parents of transition-age youth with disabilities and students with disabilities themselves regarding (a) the perceived importance of various adult goals, (b) specific types of transition-related training and skills, and (c) potential barriers.
- Results indicated parents valued teacher support more than youth, youth reported higher levels of self-esteem, more significant barriers to transition, and a greater interest in taking a future caretaking role. Last, parents and youth agreed on the goals important for transition, which included high school completion, obtaining health insurance, and access to a quality doctor.

Reed-Knight, B., Blount, R. L., & Gilleland, J. (2014). The transition of health care responsibility from parents to youth diagnosed with chronic illness: A developmental systems perspective. *Families, Systems & Health: The Journal of Collaborative Family Healthcare, 32*(2), 219-234. doi:10.1037/fsh0000039

- This article reviews research related to transition health care responsibility from parents to adolescents and young adults with disabilities and/or chronic illness.
- Factors that were consistently identified as facilitating successful transition are described.
- Implications for practice included encouraging youth to assume appropriate levels of health care responsibility, using criterion-based training to increase youths' ability to manage their own healthcare, and screening youth for psychological difficulties to allow for delivery of appropriate mental health services.

Sanabria, K. E., Ruch-Ross, H. S., Barger, J. L., Contri, D. A., & Kalichman, M. A. (2015). Transitioning youth to adult healthcare: New tools from the Illinois Transition Care Project. *Journal of Pediatric Rehabilitation Medicine, 8*, 39-51. doi:10.3233/PRM-150317

- This article presents the results from a pilot study to test the effectiveness of two curricula, one for pediatric and one for adult providers, designed to improve youth transition to adult health care.
- Results indicated improved results in all activities and for all sites, and consumer reviews reported the curricula were understandable, interesting, and effective. Implications for practice included: (a) a gradual, sustained implementation with patients; (b) education of physicians on the curriculum; (c) exposing pediatric psychiatrists to training on transition; and (d) addressing health care skills with youths in early adolescence.

Transition Planning Materials

Freeman, M., Stewart, D., Shimmell, L., Missiuna, C., Burke-Gaffney, J., Jaffer, S., & Law, M. (2015). Development and evaluation of The KIT: Keeping It Together™ for Youth (the 'Youth KIT') to assist youth with disabilities in managing information. *Child: Care, Health and Development*, 41, 222-229. doi:10.1111/cch.12199

- This article reports the results from the development and evaluation of “The KIT: Keeping It Together™ for Youth” (the Youth KIT). The Youth KIT is designed to support adolescents with disabilities as they transition to adulthood through organizing personal information, acquiring that information from others, and providing it to others when appropriate.
- Focus groups and individual interviews revealed the Youth KIT to be useful along with the themes of self-discovery for youth and the need for a good fit between youth and mentors supporting the youth as they use the Youth KIT.

Gillman, D., & Schlicht, B (2007). Transition to adult health care: A training guide in three parts In *Healthy and Ready to Work: A Series of Materials Supporting Youth With Special Health Care Needs*. Waisman Center, University of Wisconsin, University Center for Excellence in Developmental Disabilities, Madison, WI. Retrieved June 4, 2009 from <http://www.waisman.wisc.edu/cedd/cifr.html>. Training guide on how to conduct a workshop focusing on preparing youth with special health care needs for adult life. The workbook and pocket guide can be used together as:

- A self-directed study program for a young person with special health care needs who is capable of reading through the workbook and pocket guide independently and is interested in doing so
- A one-on-one teaching tool with a young person and a learning partner who can provide direction on how to use the workbook and pocket guide
- The foundation for group workshops for a variety of audiences including teens and/or young adults with special health care needs, parents of children and

youth with special health care needs, community based professionals and partners interested in working with CYSHCN and their families

Gorter, J. W., Stewart, D., Cohen, E., Hlyva, O., Morrison, A., Galuppi, B., & ... Punthakee, Z. (2015). Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: A mixed-methods longitudinal prospective cohort study. *BMJ Open*, *5*, e007553. doi:10.1136/bmjopen-2014-007553

- This mixed methods study examined the effects of two interventions, the Youth KIT and an online transition mentor, to improve self-management for youth with chronic health conditions as they transition to adult health care.
- Results indicated the interventions were perceived to have modest utility. Goal achievement and satisfaction increased throughout the course of the study.
- The authors concluded that transition supports need to be individualized and integrated into healthcare systems. Additionally, interventions that solely focus on youth will not effectively develop self-management.

Kingsnorth, S., Gall, C., Beayni, S., & Rigby, P. (2011). Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child: Care, Health and Development*, *37*, 833-840. doi:10.1111/j.1365-2214.2011.01294

- This qualitative study examined the benefits, limitations and outcomes a “Family Facilitator-led Transition Peer Support Group” on parents' knowledge, skill, and support in planning for the future.
- The parents reported that acquiring new knowledge led to active, future-oriented planning and the facilitator and social supports were valuable.

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